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A “we” problem for bioethics and the social sciences: A response to Barbara Prainsack

Abstract

In her article "The We in the Me: Solidarity in the Era of Personalized Medicine," Barbara Prainsack develops an earlier interest in the relationship between solidarity and autonomy and the way that these notions operate once passed through the lens of bioethical thought and practice. In his response to this article, Simpson introduces the perspective of two South Asian physicians on these issues. The piece highlights issues of personhood upon which the informed consent transaction is based and draws attention to the culturally specific versions of how people conceive of relationality, duty, care and the obligations they feel they owe to others. The piece highlights the pronominal shifts between the “we” and the “me” and the way that these dispositions emerge in socio-politically configured spaces. By paying careful attention to the settings and situations in which the movements between different positions actually take place, the ways in which the fabric of ethical life is made rather than simply given is revealed. Ethnographic inquiry is seen as crucial in understanding this process because it points to disjunctions between the categories that we are provided to apprehend the world and what it is actually like to live in that world.

Over quite a number of years I, a social anthropologist interested in bioethics, have been in dialogue with two doctors from South Asia. One is a professor of physiology in a university medical school in North India and the other is a senior consultant physician in a teaching hospital in southern Sri Lanka. They are both well trained in “western” medicine as well as the tradition of medical ethics that is mostly associated with it. In my estimation they talk sensibly and knowledgeably about the Hippocratic Oath, Nuremburg Code, Helsinki Declaration and the subsequent refinements of these in notions of autonomy and informed consent as they feature in contemporary therapeutic and research encounters. However, they have often spoken of a difficulty they have as doctors and medical educators when working in a South Asian context. What they need to do to be “ethical” in the sense mapped out by a western medical ethics does not sit comfortably with how they feel they should practice as doctors working in an Asian setting. Something doesn’t quite fit. If they had read Barbara Prainsack’s “The ‘we’ in the ‘me,’” they would have no doubt been helped, as I was,

to understand the nature of this conundrum. The article pinpoints how the relationship between the autonomous, rational, skin-bound individual “as the central bearer of agency in Western thought” may obscure and elide important dimensions of experience and understanding that people bring along with them when they engage with the practitioners of western biomedicine in Asian settings. My doctor friends feel it important to point out that talk of autonomy is problematic because personhood, for them and their patients, is also relational and distributed in ways that are markedly “other-directed,” to use Prainsack’s term. They might also be rather bemused to learn of the concerns about “personalized medicine” given that many of the indigenous healing traditions of South Asia, such as Ayurveda, begin explicitly with the person in establishing the most appropriate treatment and not with diseases and active ingredients. As practitioners, the issues raised in her paper are precisely the points where culturally specific ideas of kinship, care, duty, solidarity and the body as a site for the management of these sentiments necessarily comes into view. Moreover, in this other-directed embodiment there appears to be a different kind of ethical register than the self-directed one they find in the global episteme of medicine and the ethics which it carries. The article would thus have helped them frame more effectively their concerns about the absence of these important referents of the person. In other words, there is a “we” in the “me” which, for them, is falling problematically out of vision. However, there remains the problem of what to do with these concerns other than simply frame them. In this short response to Prainsack, I want to follow a line of flight which doesn’t just posit static categories in perennial opposition but draws attention to the movement between them—what this is, how it comes about and with what consequences. What I offer is thus more of a comment about the relationship between methodology and critical hermeneutics than a quest for psycho-philosophical verities: the person is not a category but a predicament and the ethical is not simply a given but is emergent within biomedical encounters. In what follows, I attempt to map out this crucial distinction.

Let us begin with Carrithers’ insightful elaboration upon Mauss’ classic essay on the notions of person and self (Mauss 1985; Carrithers 1985). In a carefully argued critique of Mauss he interrogates the terms person and self or, more precisely, the *personne* and the *moi*. The *moi* he describes as referring to conceptions of the self within a wider cosmos and as typically used to reference an inner life that is

individualistic in its formation. He defines the *personne* as “the social and legal history of the individual in respect to society as a whole” (ibid: 235). What is distinctive about this aspect of the person is the extent to which it reflects the “ordered collectivity” of which he or she is a member. In elaborating these concepts, Mauss was intent on making a specific point about the *moi*, namely that it had appeared at a particular point in history. Using textual evidence from fifth century India, Carrithers demonstrates that this was not the case. Moreover, he concludes that it is difficult to divorce the outward-looking, social individual from the inward-looking, psychic individual in the ways that Mauss attempted in his essay. What for Mauss began as a simple Durkheimian oscillation between the individual and society begins to look like a much more complex dialogue between consciousness and history. In ethnographic terms, the relationship between *moi*-theories and *personne*- theories needs to be carefully specified if it is to be understood (Laidlaw 2014:38-9).

One such specification is offered by the social anthropologist Michael Lambek who, in a recent essay, has drawn attention to two kinds of personhood: the forensic and the mimetic (Lambek 2013). He traces the notion of the person as “forensic” back to the seventeenth century English philosopher John Locke, who used this term to designate the temporally continuous and rationally accountable person. This is the “modern” person believed capable of making contracts that will endure through time and for which he or she will remain morally and legally accountable. Similar presumptions lie at the core of the consent procedures that feature in medical- and bio- ethics. In these contexts, the forensic person is the one who is deemed capable of autonomous, intentional, self-originated decisions and, moreover, can appreciate their consequences at subsequent points over time as that same person. Indeed, doubts about this particular competence provide grounds for over-riding or reallocating authority to provide informed consent. By contrast, Lambek introduces the idea of the mimetic person. Whilst this term is in many ways problematic, it references an important aspect of what it means to be a person. The term is intended to capture the routine and performative aspects of human social life which entail “embodied articulation unmediated by conscious reason” (Lambek 2013:848). In our everyday lives we can be “ourselves” in response to other persons and in multiple roles and subject positions. These responses work at different scales; sometimes they might work together and other times they may not. Carrithers suggests that an individual

who was a Christian and a German citizen in Nazi Germany may have felt an uncomfortable discrepancy when it comes to containing obligations to other citizens and to the state (Carrithers 1985:236). A more recent example can be drawn from the Charlie Hebdo massacre. In response, many people around the world were moved to carry placards proclaiming “I am Charlie” as a mark of solidarity with people opposed to the suppression of free speech. As a counter-response, many Muslims around the world carried placards proclaiming “I am not Charlie” in order to express their solidarity with those offended by cartoon representations of the prophet Muhammed. The business of protesting and counter-protesting suggests some complex operations of differentiation and collectivization in which the mimetic and forensic aspects of persons are brought into play as subjectivity continually unfolds within a single life lived in relation to the lives of others.

What is important to note in this brief reprise of Carrithers and Lambek is the essentially duplex nature of personhood. In the constitution of persons, both dimensions—forensic and mimetic, continuous and discontinuous, individual and collective, fixed and malleable—are in play or, as Carrithers would have it, in conversation (ibid 255). Second, in these conversations we need to pay careful attention to the circumstances in which the pronomial register shifts, making one identification predominate over another. These are the points at which the “we” in the “me” might be made visible such as when people participate in religion, ritual, kinship and community or, perhaps, a Charlie Hebdo march or counter-demonstration, and perhaps experience a sense of mutuality and connection as a result. Moves might also go in the opposite direction, as when the “I” is recovered from the “we” and a person makes a stand against collectively endorsed injustice or oppression.¹ Pronouns, it would seem, and how we get from one to another in practice, is something to which we should pay careful attention (Fernandez 1986; Carrithers 2008). Before considering this idea of pronomial movement in more detail, let us return to the idea of informed consent which is the starting point for Prainsack’s discussion.

Informed consent has a long history. One point of sharp focus in this history was the trial of doctors accused of vile and systematic abuse within the Third Reich—to make globally and eternally visible each individual “me” that made up the “we” of

totalitarianism. The full extent of their crimes was brought to the attention of the world in the so-called doctors' trials that began at Nuremburg on 19th August 1947. Among other things, an outcome of the trial was the Nuremburg Code. This code would ensure that state power would never again be able to strip away rights, identity, citizenship and nationhood to create a condition of absolute and abject vulnerability in which people could be reduced to a state of "bare life" (Agamben 1998: 171). In future, such acts of de-humanization perpetrated in the name of science and medicine would be avoided by making freely-given, informed consent the first premise of all biomedical and research transactions involving human subjects. In the present day, this crucial transaction has evolved into a ritual of passing back and forth information, forms and signatures, which signal that human subjects are being treated as ends in themselves and not merely as the means to an end. In ideal terms, informed consent might thus be seen as effecting a reversal of the power relation between the doctor and the research participant/ patient such that the latter is now in the ascendant (Kelly 2003:184). Yet, what is going on in practical terms? One of the main things that I would suggest is happening is that people are being asked to think. They are being asked to process information, options and consequences for themselves and for others. Perhaps unsurprisingly, given that thinking is a notoriously unruly and highly discursive process, thinking in the context of informed consent procedures has been interrogated only minimally.

Following Arendt, and her posthumously published meditations on "The Life of the Mind," we might consider thinking as taking one of two forms: the "two in one," that is, thinking in isolation, or the "dialogue of thought," that is, thinking with the help of others (Arendt 1971). Sticking with Arendt for a moment, this formulation makes the procedure for informed consent not merely a passive inoculation against vulnerability but an educative act and therefore a political one. As Arendt puts it: "if ...().. the ability to tell right from wrong should turn out to have anything to do with the ability to think then we must be able to 'demand' its exercise from every sane person, no matter how erudite or ignorant, intelligent or stupid he happens to be" (ibid 13). As such, the act of eliciting informed consent is one in which certain aspects of personhood become fixed, rather in the way that a photographic image is fixed in the developer's tray: it provides evidence of something beyond itself. I would suggest that the image that appears is of the forensic person, that is, the one that will be held

to account or, indeed, will be capable of holding others to account for things done to them in the future. What is not easily reckoned with in this particular mental process is Arendt's second kind of thinking, the kind that goes on together with others. This is, the other-directed thinking that is woven into the dense fabric of a person's connections with kin, community and surroundings. This kind of thinking brings in the day to day being with others and the attendant skills of reading their thoughts, action and intentions. At root, the difficulty of incorporating this dimension into contemporary bioethics is a very important intellectual problem for Prainsack and me but, for my Asian doctor friends, it is also a very practical one.

Prainsack's two examples are instructive when it comes to getting further into the nature of this problem. Her first example draws on an ethnography produced by Koenig & Gates-Williams and is set in multicultural San Francisco. They point out that there are protocols that doctors must follow as their patients begin to reach the end of their lives. These directions ensure that, in Agamben's terms, the weak and vulnerable are not treated as "bare life" by unfeeling medical practitioners. The unintended consequence pointed out by Prainsack is that distress is caused by seeming to deny the importance of people and things that are manifestly important to the patient. The problem is presented by Prainsack in terms of a "clash" between "protocols" and "social and cultural norms." However, I would suggest that this is rather more than a "clash." It arises out of the cultivation of a kind of thinking in which the objective is to make a particular kind of person appear. This is the kind of person that is integral to the functioning of the modern state and upon which the idea of rights that are distinctively "human" are built and elaborated (cf. Gear 2006; Yeatman 2000). Without such persons the rational, jural, liberal, bureaucratic principles on which large political and economic formations depend would cease to function. In Lambek's terms, these are persons who, however fleetingly, are rendered forensic, continuous, individual and fixed. For people to engage with this process it is to be caught in a gaze that is not easily evaded, as it is deeply imbricated in the institutions that hold modern states together. For ethnic minorities in San Francisco or Asian doctors trained in western medicine and practicing in their home countries, there is an uncomfortable tension lurking here. Participation in the rituals of informed consent appear to invite internal thinking and, to use Foucauldian coinage, invites new modes of subjectivation. These changes are brought about in ways that over-ride the

more familiar and available routes to shared thinking (religion, kinship, community, daily practice). For example, in the normal run of things, to be “alone” (*taniyama*) for a Sri Lankan person is an unusual and problematic state. It has often struck me that the act of eliciting informed consent pulls such people into a sense of aloneness at the very points of crisis at which they would typically seek to orientate themselves maximally to others (Sariola and Simpson 2011). In short, the singular, transcultural, universal “I” of law, medical ethics and, by extension, human rights, must be set apart from the multiplicity of forms that the “we” in which I dwell might take. The rights, citizenship, freedom, autonomy and so forth that guarantee my security within the modern nation state may not always sit comfortably with the sense of ontological security which I derive and sustain from being with others in the world.

Prainsack’s second example takes up the theme of organ donation and points to another set of important pronomial shifts. Typically, the educative intent in relation to this practice has been to move people from “me” to “we.” That is, to voluntarily connect a person’s organs and tissues through altruistic acts of gifting to the broader imaginaries of nation, people, and community. Blood donation as outlined by Titmuss is the classic paradigm of this version of altruistic giving. However, the circumstances to which Prainsack draws our attention render the act of donation significantly more complicated. On the one hand, she refers to kidney donation, an act that is altogether more costly in physical and emotional terms than blood donation. On the other, she discusses cases of directed donation, that is, ones where there is something more than “society” as the endpoint, as donor and recipient may well be in a relationship that is known or specifiable. The “we” that might come into view here is clearly not, in Prainsack and Buyx’s terms, the “tier 3” solidarity of an imagined nation of the kind that Titmuss had in mind. On the contrary, directed-donation seems to hover problematically between their “tier 1” solidarity (between individuals) and “tier 2” solidarity (within groups and communities) and, furthermore, does so in ways in which self-interest and altruism become difficult to delineate (Prainsack & Buyx 2011; also see Kaufman 2014). The rhetorical push here is therefore not to realize the “I” in the “we” (that is, to highlight the forensic person against a backdrop of quotidian and fluid practices) or the “we” in the “me” (that is, to foreground aspects of the mimetic person that might otherwise be lost in the workings of bureaucracy), but rather to track carefully and in detail the realization of one kind of “we” within

another kind of “we” (that is, to move the person between different mimetic registers). Such moves are of great methodological interest because they signal a kind of world building or human becoming that ethnography is ideally suited to capture. They relate to scales that are often lost in the traffic of macro-structural processes. Prainsack gives a striking example: Sandra, an American Christian woman, who, upon reading of Yitzhak, an Israeli man with kidney disease, hears an instruction from God and offers Yitzhak her kidney, which, after some deliberation by an Israeli hospital ethics committee, is gratefully accepted as an “altruistic” gift. Thereafter, Sandra and Yitzhak enjoy a very literal sense of connection. In other words, these are moves that often confound the vertical moves that bring persons into existence as citizens and rights-bearing individuals and which are presumed to be regulated, shaped and mediated by the institutions of law and medicine in large scale state formations.

My two doctor friends would have followed this line of argument with interest. They understand the importance of the forensic person in the work that they do but are also aware of the acts of sublimation they must perform on their patients in making it appear. Left behind are actions, relationships and solidarities typically expressed in familiar idioms of culture, religion, kinship and community. They would agree with Prainsack that this is a problem with “the Western focus on self-interested independent individuals” and not with autonomy *per se*. Where they would differ is in two important respects. First, in the contexts in which they operate, the highly individualized version of ethics that comes with Western medicine can offer little in the face of the gross inequities, neglect, mal-distribution of resources and corruption with which public medical systems across South Asia must contend. Gupta puts his finger on the problem in his ethnographic account of the ways in which Indian bureaucracy causes large numbers of people to perish for want of food, health care and basic sanitation and despite the avowed intent of the post-colonial state to serve its people to rather different ends (Gupta 2012). These concerns originate in the kind of structural inadequacies in baseline public health provision that do not generally trouble doctors working in more affluent settings. The second difference takes us back once again to the question of informed consent and the kinds of care that this transaction has come to signal. A useful distinction to introduce at this point is between the notion of “caring about” and “caring for.” This distinction has been elaborated in the context of organ donation in a recent

essay by Atkinson, who outlines acts of “caring-for” as responses to known and proximate others whereas “caring-about” typically references concerns beyond the immediacy of everyday lives (Atkinson 2016).² Put simply, where informed consent is concerned, doctors must first signal that they “care about” the forensic person before they can begin to “care for” the mimetic person they have before them. The Asian doctors’ concern is that, in their world, they might end up being drawn into “caring about” when “caring for” is what they feel they should be practicing, as well as preaching.

In responding to Prainsack’s article, I have argued, like her, that reflecting on the “we” in the “me” is an important starting point for a critique of bioethics. Using the voice of my Indian doctor friends, I have tried to take things further by highlighting some of the complexities that underpin this important pronomial shift. First, the “we” is shot through with culturally specific versions of how people conceive of relationality, duty, care and the obligations they feel they owe to others. Second, the “me” from which these dispositions arise is not a stable or constant but is itself highly variable and situated. Third, both the “we” and the “me” emerge in socio-politically configured spaces. Paying careful attention to the settings and situations in which movements between these different positions actually take place reveals the ways in which the fabric of ethical life is made rather than simply given. Finally, the work of ethnographic inquiry is important in understanding this process because it points to disjunctions between the categories that we are provided with to apprehend the world and what it is actually like to live in that world

Endnotes

1. Lienhardt offers an account of how the Dinka of Southern Sudan conceptualize the self. Through an analysis of proverbs and folktales as well as his personal encounters with the Dinka he charts something like a Dinka conception of the self in relation to the collectivities that typically elide more individualistic accounts of personhood in small-scale traditional communities (Lienhardt 1985).
2. I am grateful to Claudia Merli for pointing out an earlier genealogy of this distinction, which goes back to Heidegger’s notion of being-in-the-world (*dasein*) and was built

on the idea of caring for others. The notion was subsequently taken up in feminist analyses to signal an appropriation of “caring for” in the face of “caring about” as the more detached responsibilities implicit in patriarchy (Maihofer 1998).

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